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KEY PARAMETERS FOR IDENTIFYING ELECTRONIC HEALTH RECORDS WITHOUT VIOLATING PRIVACY

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ABSTRACT

There is a critical need to identify electronic health records without compromising the privacy and confidentiality of patient data. This white paper discusses important possible parameters associated with electronic health records that could be used for this identification. The core objective of this white paper is to set a stage for the development of IEEE standards associated with the identification of electronic health records, thereby discussing the feasibility and potential stakeholders for such standards.

1. GENERAL OVERVIEW OF ELECTRONIC HEALTH RECORD IDENTIFICATION

Electronic health records and electronic health record systems (Gurupur, [1]) has been defined by IEEE standards.[1] It is to be noted that the IEEE Standards Industry Connection workgroup on Data Quality Standards for Electronic Health Records was created in 2023 for the purpose of developing international standards for electronic health records, ultimately leading to seamless flow and interoperability of electronic health records. It is to be noted that standards for general identification of electronic health records without interfering with a patient's privacy are necessary.

Health records in the United States are considered facility-specific, and patients are universally identified by name (last, first) and date of birth. In rare instances, two patients are identified with the same name (last, first) and date of birth. In this instance, the facility will also broaden the search to include a middle name. In Germany, health records are considered practitioner-specific, individually identified by the full name and home address of the patient. However, records are also cross-referencing the patient's insurance number, as less than 0.1% of citizens are considered to be non-insured [2]and unable to match. Clinical records consist of separate records held by the respective clinic. Therefore, it is important to note that different countries and organizations use different identification systems to generate unique identifiers for identifying patients. Additionally, we need to accept the fact that several factors outside the health record system might affect the identification process.

1.1. CHALLENGES ASSOCIATED WITH ELECTRONIC HEALTH RECORD IDENTIFICATION

Due to legislation in Europe and GDPR as a baseline for consent-based data access and usage, countries already providing electronic health record services, as well as countries with a future rollout roadmap, focus on patient-centric access processes. In Germany, according to the current timeline, a rollout of electronic patient records (ePA System) will start in 2025 [3]. Records will be primarily identified based on personal data called KVNR [4], consisting of InsurantId or patientID [5] as well as a Home CommunityID, which references the record-keeping system or its provider [6]. As patients govern both access and data sharing with practitioners themselves, the actual access to a health record is granted during a visit to a doctor's office [7] while presenting a patient-owned eGK (smartcard provided by the insurer) or using the ePA-App.

[1] Numbers in brackets correspond to the publications listed in Section 4.

Within Austria, electronic health records (ELGaA System) were established more than ten years ago, featuring indexes for patient data (L-PI and Z-PI), which also act as a clearing system [8]. Access to and identification of health records is possible for registered practitioners via a contact confirmation service, which is triggered by physical authorization using the patient-owned e-card (smartcard issued to citizens) and has been enforced in 2023 [9]. Identification takes place by utilizing the social security number (SVNR) [10].

1.2. PLACE AND TIME OF ELECTRONIC HEALTH RECORD IDENTIFICATION

Facilities in the United States are required by the government to utilize certified electronic health record systems. In order to be considered certified electronic health record technology (CEHRT) within the United States, the Centers for Medicare and Medicaid Services (CMS) and Office of the National Coordinator (ONC) established a standard system that developers must meet in order to qualify. The standard is known as the Health Data, Technology, and Interoperability: Certification Program Updates, Algorithm Transparency, and Information Sharing (HTI-1) Final Rule [11]. This rule states the requirement that "any network time protocol (NTP) standard to be used that can ensure a system clock has been synchronized and meets time accuracy requirements." The German eHealth provider Gematik follows a similar approach and provides a component for records management [12], which ensures that only governed access is possible. A subcomponent is responsible for centralized time management within the ecosystem whilst being compatible with NTP4 [13].

2. KEY PARAMETERS ASSOCIATED WITH IDENTIFYING ELECTRONIC HEALTH RECORDS

The United States has been working on several challenges associated with electronic health record identification over the past 25 years. The first challenge was confusion over healthcare professionals using acronyms interchangeably—EMR (Electronic Medical Record), EPR (Electronic Patient Record), and EHR (Electronic Health Record) [14]. The three acronyms were seen to represent the same set of data but do not comply with the definitions set forth by the International Organization for Standardization (ISO). ISO clarified the EHR to be defined as follows: "Information relevant to the wellness, health, and healthcare of an individual, in computer-processable form and represented according to a standardized information model, or the longitudinal electronic record of an individual that contains or virtually interlines to data in multiple EMRs and EPRs which is to be shared and/or interoperable across healthcare settings and is patient-centric." [15]

With the naming convention established, other challenges are now being addressed. The primary (and persistent) challenge is the accuracy of identifying the patient. When a patient presents to a care provider, the first opportunity for misidentification appears. The facility first completely relies on the integrity of the information provided by the patient (last name, first name, date of birth). The facility, secondarily, relies on staff to enter the data correctly into the system to locate the patient. The record-matching functionality at the facility level can be done either manually or automatically, depending on the system utilized. Some software applications can automatically match health records and also make suggestions on potential matches (using part or whole of the data provided). The matching challenge arises when a patient provides a nickname versus a legal name at the initial point of contact and uses the nickname and legal name interchangeably at different points of care. To further complicate this challenge, a last name is changed either through marriage, adoption, or other personal reasons. [16]

Currently, there is proposed legislation to both the House and Senate that is intended to alleviate these issues. (H.R. 7379 – The Patient Matching and Transparency in Certified Health IT (MATCH IT) Act of 2024 [17]). This bill has been proposed by the American Health Information Management Association (AHIMA). The bill is sponsored in the House by Rep Mike Kelly (R-PA-16), Rep Bill Foster (D-IL-11), and Rep Blain Luetkemeyer (R-MO-3). There are currently no sponsors in the Senate. If passed, the MATCH IT Act will define a patient match rate, establish an industry standard data set to improve patient matching, update health IT certification requirements, and promote interoperability requirements.

There are currently no standards in place to allow for comparison of misidentification of electronic health records. If passed, the measure will instruct the Office of the National Coordinator for Health IT (ONC) to define the minimum demographic data set to be deployed and utilized by all care providers nationwide. In Germany, the KVNR and its 10-digit, persistent part is carried by each patient for a lifetime period. Together with additional data, it serves as the primary identifier across insurance policies and practitioners, as well as all interactions with the ePA [18]Austria relies on the social security number (SVNR) as identification, either presented manually or using the e-Card [19]. Both of these exemplary European countries use fiscal or insurance information for identification, which means that a very critical data point serves as a key identifier for a patient and health records as it is handed over between practitioners and their respective record-keeping systems.

2.1. PLACE AND TIME OF ELECTRONIC HEALTH RECORD IDENTIFICATION

The place and time of electronic health record creation are often managed by individual electronic health record systems. These systems adhere to the standards enforced by the designers or the developers of those systems. It is possible that different versions of the system may also adhere to different formats creating undesirable situations in the identification of the electronic health records. This could also be attributed to the fact that many defined processes within a healthcare unit may not take into consideration the formats and standards used for electronic health data. Therefore, there is a critical need for the inclusion and implementation of usable and clear standards in electronic health record identification.

Regarding creation, both Germany and Austria follow an automated approach. A patient's EHR is being created by default but may become obsolete if an opt-out is executed [20], [21]. While it is already in place in Austria, this automated creation is scheduled for January 2025 in Germany. In both of these adjacent countries, identification takes place at the practitioner or clinic using a physical medium (Gesundheitskarte "eGK" in Germany, "e-card" in Austria) for authentication, mainly using the insurantID/KVNR or social security number/SVNR, respectively.

2.2. IDENTIFYING THE SYSTEM USED TO CREATE THE ELECTRONIC HEALTH RECORD

The system used to create the Electronic Health Record in the United States can vary depending on the size and scope of the facility. The EHR contains patient-level data registries (i.e., demographics, diagnoses, problem lists, medications, vital signs, and ancillary test data) and assists in core functions such as order/result management, clinical decision support, electronic communication, population health reporting, patient support, health information exchange, and administrative processes. The Meaningful Use initiative began in 2011 to create a pathway for healthcare providers to implement an EHR. Meaningful Use attempted to propel facilities to design and launch EHR-based registries that could integrate or link to other EHRs and patient registries [22] This process has been lagging despite the incentives put forth by the Meaningful Use program. Slowly and organically, disparate healthcare systems have started banding together through the cooperative use of EHR systems. This cooperative use is allowing these different organizations to "break the glass" to access patient information not innately created.

As Germany follows a centralized approach, the identification of systems used for creating the health record would theoretically be possible without explicit authorization from the patient. The creator of an electronic health record is recorded by a combination of IDs (LANR, KVNR, SystemID).

In Austria, the creator of an electronic health record is displayed within the GDA part of the EHR dashboard, which is accessible for the patient and, if authorized, for practitioners as well. This frontend also acts as an aggregator of data from the decentralized ELGA system because there is no centralized storage of EHRs, meaning ELGA serves mainly as a broker within the ecosystem while the actual data is held within the local system of the practitioner or clinic. With the adoption of FHIR and the international alignment with IPS as a standard for patient summaries, the data field healthcare provider (HCP) may serve as a data point for the identification of EHR origin. However, implementation of cross-border health services is ongoing and, within the EU, subject to individual roadmaps [23].

2.3. CHALLENGES ASSOCIATED WITH ELECTRONIC HEALTH RECORD IDENTIFICATION

In order to identify aspects of a health record, such as authenticity, source, or originating system, the health record system should provide a clearing interface. Within the sector of vehicle registrations in Germany and Austria, common centralized clearing systems provide the possibility to identify the insurance company that is linked to the number plate. Although no personal data is being exchanged (such as, i.e., registrant name or vehicle owner, insurant ID, or fiscal information), the authenticity of the nameplate (which acts as proof for the insurance record), as well as the insurance company responsible for claims, can be verified [24] [25]. Within Europe, the European Health Data Space EHDS may develop such services [26], depending on its design within the next years until its official launch. As an example, Finland has developed a national data clearinghouse providing relevant services [27].

As these examples from several medical record management systems show, record verification often depends on interaction with the patient and situational access provisioning. This presents a challenge, as any medical record access must pass individual consent or need to be cleared by the authorization mechanisms provided to the patient only.

3. CONCLUSION

In this white paper, the groundwork has been laid for a discussion on key parameters associated with the identification of electronic health records from a general application layer perspective. The details of these identifying factors need further exploration. In addition to this, there is a certain need for developing international standards on this topic. The core contributions of this white paper are as follows: 1) addition to the body of knowledge with regards to the discussion on the identification of electronic health records possibly leading to key policy and decision-making for private and government institutions, and 2) setting the stage for the development of IEEE standards for the identification of electronic health records. It is believed that this work will be further explored in areas of health record security and other important concepts [28].

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